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ABSTRACT

The literature on coping with stressful life events and the literature on parental issues related to the birth of a handicapped child suggest that such variables as understanding of the nature, intensity, and duration of parental responses figure prominently in their adjustment to the disability. The development of support programs designed to improve the parents' coping strategies, to improve their perceptions of the child and of their own abilities to deal with stress, and to improve their ability to regain a sense of control in their lives are critical for successful reduction of parental stress. Social workers can help parents through this process by helping them to see the child's behavior in different, more positive ways, to assess children's behavior and identify specific target behaviors, and to develop behavior management skills (such as use of verbal cues, positive comments, reinforcement techniques, modeling, guided participation, response cost, "time outs," and punishment). (CB)

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Stress Associated with Handicapped Children: Guidelines for Family Management

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Stress Associated with Handicapped Children: Guidelines for Family Management

Introduction

The birth of a child is a time of excitement and apprehension for every family. There is excitement in the wonders of the creation of a new being--from conception through the birth process. Excitement surrounds the expectations that are formed as the child successfully masters each stage of development. There is also the apprehension that each family feels concerning the new financial, emotional and educational responsibilities of rearing a child.

The impact of the birth of a handicapped child upon the family unit is strongly felt by all members. They may react with shock, disappointment, guilt, anger, depression, and/or confusion. Schleifer (1982) describes the reactions of parents to the birth of a handicapped baby:

> Couples have daydreams and images of what this new stage of parenting will bring. Joyful images are modified by the real experiences of parenting. The couple must also make a different kind of commitment to each other and the baby. They will have to resolve how they will work together so that the interests of each can be met. The birth of a child with a serious difficulty complicates this process. First the images of themselves as parents are likely to be changed. This time that would have brought pleasures brings doubts and worries. The ordinary difficulties of helping any child grow arouse frustration and helplessness at some point in all couples. But when parents are having greater difficulty, they find themselves preoccupied with their own efforts and especially their feelings of frustration. (p. 44)

Lombana and Lombana (1982) state that parents of handicapped children tend to experience more stress or physiological tension. Holmes and Rahe (1967) in their study of stress and its effects on a person's physical health ranked stressful events (see Table 1). Items 11 and 14 are directly related to the study of parental stress and indicate that levels of stress will increase with the arrival of an infant with mental, physical, or sensory impairments.

Sources of Stress

The emotional, social, educational, and economic demands made on families of handicapped children make them particularly vulnerable to stress. Smith (1984) identified the following factors as possible sources of stress:

Dream of child shattered
Child looks different
More attention required
Routine caregiving is more difficult
Attitudes towards handicapped
Exposed to frustrations and humiliations
Lowered self-esteem
Less time for siblings
Spouses have less time together
Friends uncomfortable/drift away
Avoid situations/social events
Fewer rewards for being a parent
Separations/disruptions of parent-child relationship
Reactions of relatives/family
Lack of specific information
Increased costs for medical, special equipment, and trips
Conflict in opinions
Parents' expectations often inappropriate
Break in communication/relationship with child
Unknown questions regarding future
Vulnerable child

Dyson and Fewell (1986) found that parents of preschool handicapped children experienced more stress than parents of

Table 1

Stress

Rank	Life Event	Mean	Rank	Life Event	Mean
1	Death of spouse	100	24	Trouble with in-laws	29
2	Divorce	73	25	Outstanding personal achievement	28
3	Marital separation	65	26	Wife begins or stops work	26
4	Jail term	63	27	Begin or end school	26
5	Death of a close family member	63	28	Change in living conditions	25
6	Personal injury or illness	53	29	Revision of personal habits	24
7	Marriage	50	30	Trouble with boss	23
8	Fired at work	47	31	Change in work hrs. or conditions	20
9	Marital recon.	45	32	Change in residence	20
10	Retirement	45	33	Change in schools	20
11	Change in health of family member	44	34	Change in recreation	19
12	Pregnancy	40	35	Change in church activities	19
13	Sex difficulties	39	36	Change in social activities	18
14	Gain of new family member	39	37	Mortgage or loan less than $10,000	17
15	Business readjust.	39	38	Change in sleeping habits	16
16	Change in financial state	38	39	Change in number of family get-togethers	15
17	Death of close friend	37	40	Change in eating habits	15
18	Change in line of work	36	41	Vacation	13
19	Change in number of arguments with spouse	35	42	Christmas	12
20	Mortgage over $10,000	31	43	Minor violations of the law	11
21	Foreclosure of mortgage or loan	30			
22	Change in respon. at work	29			
23	Son or daughter leaving home	29			

SOURCE: Chart originally published in "The Social Rating Scale" by T. H. Holmes and R. H. Rahe, 1967, Journal of Psychosomatic Research, 11, 213-218.

nonhandicapped children. The sources of this stress were identified as the child characteristics, physical incapacitation, parental pessimism in relation to the child, and the severity of the child's handicap. There was a moderately high negative relationship observed between the amount of social support and stress level. This finding provides support for services which may moderate stress.

Beckman (1983) found that responsiveness, temperament, repetitive behavior patterns, and the presence of additional or unusual caregiving demands were related to the amount of parental stress reported. Single parents reported higher levels of stress than did two-parent families primarily on the basis of caregiving. In the two-parent family, relief in the form of another parent is available.

Beckman, Polorni, Maza, and Balzer-Martin (1986) and Blacher, Nihira and Meyers (1987) found that the impact of the handicapped child varied according to the needs of the child and that stress was not a static phenomena. In the first study, more parent and family problems were reported with infants in high risk categories. Families of these children utilized support networks during situational crises. In the second study, it was found that the birth of a severely retarded child creates a source of high and relatively constant stress for families. With higher level functioning retarded children, the levels of stress tended to decrease with age. Burr (1982) suggested that the continual burden of care presented by the severely impaired child and the

greater degrees of family adjustment tend to prevent the family unit from returning to "normal" routines. Families with severely retarded children tend to be more committed to the child and less to the family as a whole. The home environments of these children were found to be supportive of child growth (Blacher, Nihira, & Meyers, 1987). In both studies, it was found that communications between parents became increasingly centered around the disabled child. In a previous study, Levy-Shiff (1986) found that the presence of a retarded child in the family may affect all dimensions of the family interactional system. In this study, it was found that the mothers were the primary caregivers and differed more from mothers of normal children than did fathers. Mothers' concern centered around the emotional strains of caregiving, the adjustment of daily routines, and the additional time involved in caregiving. Parents were found to spend a greater proportion of their communications on issues related to the handicapped child. Although these child focused interchanges may aid in solving some of the urgent needs of the child, they may exert unfavorable influences on the marital link leaving little time or energy to invest in the family bond.

Parental Reactions

The reactions which parents have to their handicapped child has frequently been discussed in terms of a "stages model." This model "proports that parents of children with handicaps experience emotional reactions in some sort of ordered sequence of discrete stages. The most common of these models describes

the stages as: (1) shock or denial, (2) guilt, (3) despair, (4) depression, (5) disappointment, and (6) acceptance or adjustment. This approach, which has proven useful to some degrees, has met resistance based on at least two factors (Allen & Affleck, 1985; Blacher, 1984; Featherstone, 1980; Searl, 1978; Wikler, Wasow, & Hartfield, 1981).

First, the definitions of the stages are often confused and there is little justification for imposing a stage model. The stage model may, in fact, cause professionals to develop over-generalizations or misleading expectations of parents (Allen & Affleck, 1985). Secondly, the stages model is not supported by research on adjustments to other aversive life experiences. The emotional responses may not build to a final adjustment or acceptance. Levels of stress should be considered in the context of a single point in time while adjustment could be considered in the broader life-span.

In a recent study by Eden-Piercy, Blacher, and Eyman (1986), the stages model was not verified. Rather, three categories of parental responses were identified:

Category 1: Shock-Guilt-Despair
Category 2: Refusal-Denial
Category 3: Adjustment-Recovery-Acceptance

This study does not suggest the presence of stages, but merely suggests that discrete categories of responses exist. By acknowledging the category of parental response, the supportive professional can better develop strategies for dealing with problems which parents are experiencing at that point in time.

In summary, the literature on coping with stressful life events and the literature on parental stress as related to the birth of a handicapped child suggests that certain variables including understanding the nature, intensity, and duration of parental responses figure prominently in their adjustment. The development of support programs designed to improve the parents' coping strategies, to improve their perceptions of the child and of their own abilities to deal with stress, and to improve their ability to regain a sense of control in their lives are critical for successful reduction of parental stress. Caretaking demands on the parents, lack of respite care facilities and lack of perceived support services tend to create the greatest amount of stress. It is also important to remember that each crisis must be evaluated individually by the support professional rather than generalized to the stage model.

Assisting Parents in Specifying Behavior

Social workers are in an excellent position to recommend specifying strategies to parents. Parents and guardians desiring to assist their handicapped children in changing their behavior must first identify and specify the behavior to be changed. Identifying and specifying refers to giving a clear, precise description of what your children are doing. It is not a listing of possible personality descriptors.

Personality descriptors are too general and vague to give useful information in helping children change. Such descriptors convey many misleading images. Descriptive labels or depressed,

has a bad attitude, has temper tantrums, aggressive hyperactive, outstanding student, and hostile give us little concrete information about what the child is really doing. Therefore, it is crucial to clearly specify the exact behaviors you wish to change. Instead of telling Tom he is bad because he threw his toy at his sister, tell him, "I don't want you to throw your toys at your sister because you could hurt her." Learning how to specify behavior is a very important skill to develop in parents.

To assist parents in refining their specifying skills ask three important questions about the child's behavior.

1. Can I count the number of times that the behavior occurs in days, hours, minutes or seconds? (Your answer should be yes.)
2. Can a complete stranger know what to exactly look for when you tell him/her the behavior you are describing? (Your answer should be yes.)
3. Can you break down the behavioral description into smaller segments? (Your answer should be no.)

Item 3 is often where the biggest breakdown occurs.

General Descriptors (can be broken into smaller segments) (avoid using these)	Specific Descriptors (cannot be broken into smaller segments) (use these)
model student	follows teacher's directions hands in all assignments earns A grades in all subjects

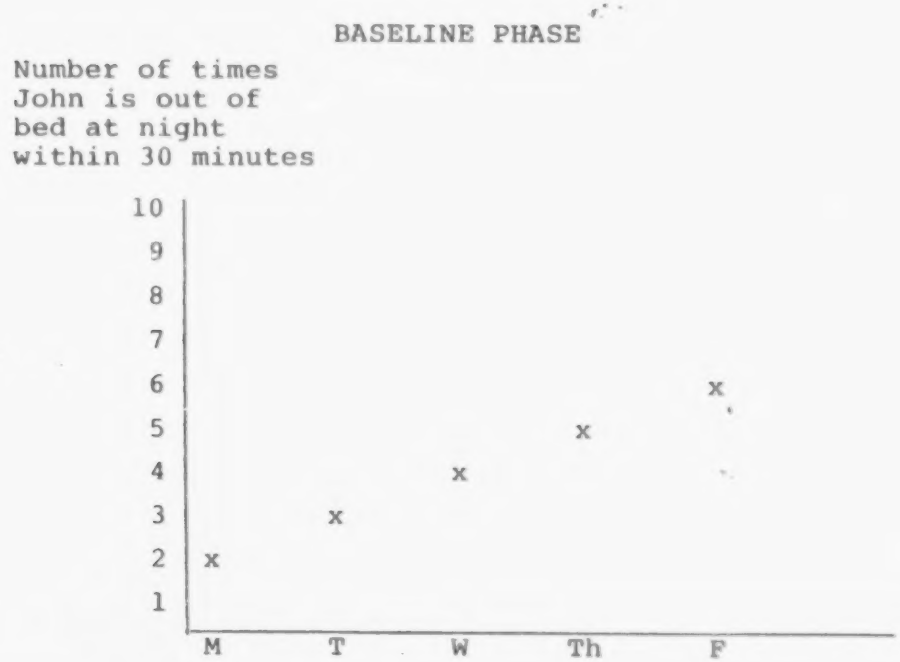
General Descriptors (con't)	Specific Descriptors (con't)
aggressive	hits others breaks objects bites others hits self yells at other children
hyperactive	out of seat every 20 seconds does not finish games does not finish assignments does not stay in line when going to and from class constantly moving in chair
has a behavior problem	wets bed soils bed does not follow parents' instructions within 60 seconds of request
withdraw	stares into space for 30 minutes or longer does not play with other children does not talk to peers does not talk to teacher does not ask any questions at home
disrupts	interrupts teacher when she is already talking pulls Sally's hair throws books on floor hums loudly when asked a question

Additionally, parents should attempt to specify behavior positively. For example, instead of reducing the number of interruptions in conversation at home, parents could easily count the number of times their son waits to speak when others are speaking. Instead of reducing the number of school absences, parents could count the number of times their daughter was in attendance at school. Stating specific behavior positively can create a more accepting and positive home atmosphere.

Assisting Parents in Measuring Behavior

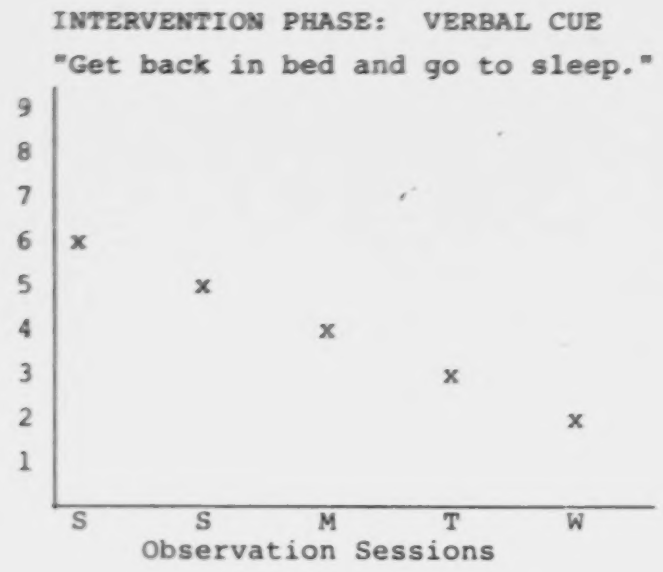
Accurate measurement of behavior is a crucial aspect in evaluating and implementing effective behavioral change programs for handicapped children. Parents utilizing these techniques can obtain accurate feedback on the progress of their children. Collection of such information provides clear and simple progress data to both parents, teachers and children.

There are two phases to accurate behavioral data collection. Phase 1, or the baseline phase, consists of measuring child behavior prior to implementing behavioral change techniques.



This baseline data shows that John was out of his bed on Monday night, 2 times; Tuesday night, 3 times; Wednesday night, 4 times; Thursday night, 5 times; and Friday night, 6 times

within 30 minutes of going to bed. If our goal is to reduce the number of times John gets out of bed at night within the first 30 minutes of being put to bed we must decide on an intervention technique to use consistently. When we decide on an intervention strategy to reduce the number of times John gets out of bed we are measuring the intervention phase of our behavior change program.



This intervention data state that John was out of his bed on Saturday night, 6 times; Sunday night, 5 times; Monday night, 4 times; Tuesday night, 3 times; and Wednesday night, 2 times. It appears that the intervention of giving John a verbal cue to get back to bed is reducing the number of times John is getting out of bed at night within 30 minutes. As we look at our intervention data we can hopefully see if the intervention technique is effective or not. So far it appears that from

Saturday to Wednesday that John is getting out of bed fewer times. We would want to continue using this intervention to see if it remains at one or goes to zero. Another five days of data collection would be useful. Constructing a simple graph or chart allows for a quick look at baseline and intervention data.

Suggested Management Techniques for Handicapped Children

Here is a hierarchy of interventions social workers can teach parents to utilize in helping handicapped children function better in the world.

Verbal cues. Verbal cues are easily understood statements made to children. Parents are real good at telling their children what not to do. For example, "Jimmy, quit teasing your sister," or "Peggy, stop running around the room." But some children need additional information telling them what they should be doing. In addition to telling Jimmy to quit teasing his sister his parents may add "I want you to go outside and play with your friend Fred." One trap parents must constantly look out for has to do with how many directions can your children follow: 1, 2, 3, 4, more or less?

Positive comments. Positive, encouraging comments often keep handicapped children trying and completing many desirable behaviors at home. One must always remember that positive comments must be sincere and earned by the child. Many handicapped children have poor self concepts and are not used to hearing that they have done something well. Words such as

"good," "yes," "O.K.," "correct," "excellent" and "keep going" can provide the drive in some children to keep them trying. Sentences can also convey encouraging messages to children: "I'm glad you picked up your room. It really looks great!" Comments of this nature should be paired with many of the other management strategies mentioned. Positive comments make children who earn them very proud and can communicate a message of positive parenting.

Earned edibles. Edible reinforcers are extremely powerful for all children. They can be simple and easy to administer and can increase the social interaction between parent or teacher. They are universally liked and can be used successfully at home or in school settings. For example, when Cheryl completes her math homework she earns five cookies. Or, when Andrew completes one school week without complaining to the teacher about the assignments he earns a Coke. Conversely, parents may object to their use because of dietary, medical or dental reasons. Edibles can be expensive and may be difficult to store because of extreme temperature conditions. Although edible reinforcers can be used in almost any setting we must also be aware of their possible shortcomings.

Earned materials. Earned materials or tangible reinforcers can be used with all types of children. It is often possible to find effective material reinforcers for any age of child. A wide variety of potential items exists at a number of differing prices. Children whom social attention and activities are not

reinforcing may be reinforced by material objects. For instance, Charles earns a baseball bat when he attends school for forty days in a row without absences. Or, Sue earns a Bruce Springsteen poster for carrying out her parents' verbal instruction without complaining for three weeks. Additionally, children may receive the item to keep or earn the right to use them without owning them. In some instances it may be easier and cheaper to rent roller skates or ice skates instead of purchasing them.

Earned activities. Earned activities or activity reinforcers is a positive strategy that is very powerful with handicapped children. Such activities are contingent upon the completion of a desirable behavior. For example, when Tom does not have a temper tantrum (rolls on the floor, screams and cries) in the grocery store then he earns a 30 minute trip to the park, or a 30 minute trip to see the trains. Another illustration of earned activities consists of Sally earning the right to see a movie because she completed all her homework assignments for six weeks and obtained an average of 80 on her two Texas Government exams. Earned activities are readily available and many are not very expensive.

Token reinforcement. The use of token reinforcement is a technique that attempts to delay gratification of handicapped children. The token may be a point, a poker chip, a ticket, a MacDonald's coupon or in the form of an allowance. As tokens are earned they signal to the child that reinforcement is coming. When and where it will occur usually is up to the parent or

teacher. Tokens are exchanged for other reinforcers. For example, a MacDonald's coupon is often put towards the purchase of a hamburger, drink, or french fries. A dollar is used to purchase goods and services at some future date. However, token reinforcers can teach children the concepts of saving and worth. Some children want to exchange their tokens for goods and services much faster than other children.

Modeling. Modeling or demonstration learning is a nonpunitive technique in which a child is shown each step of a desired behavior. After watching a model perform the behavior, the child must demonstrate the behavior to a parent, teacher or peer. For example, if a child is learning to wash their hands, the process of turning on the water, picking up the soap, rubbing the soap on both hands and fingers, putting down the soap, rinsing the soap off the hands and fingers, turning off the water, and drying hands may be demonstrated. After the demonstration the child performs the task with the assistance of a model. In many daily living situations handicapped children can learn many skills by watching parents, teachers or peers. In many situations, action speaks louder than words.

Guided participation. Guided participation is another modeling technique used to shape the behavior of handicapped children. Parents, teachers, peers, tape recordings, filmstrips, video tape, or films may be effective in helping children learn many positive behaviors. After watching a model the child may begin to demonstrate the desirable behavior. As they forget

other steps they may refer back to the model person or AV material for assistance. It may be used to teach children math, reading, how to tie shoes, how to dress themselves, etc. Children can learn and progress at their own pace. For children who are fearful of parent, teacher or peer criticism utilization of appropriate AV materials may eliminate such fears.

Contracting. Contracting is a strategy whereby an agreement is made between two parties. Agreements may be verbal, pictorial and in writing. All provisions of the contract must be clearly understood by the child and parent and/or guardian. Contracting may be used with young children and older adolescents. If clarity is a problem parents should attempt another procedure.

Intentional ignoring. Intentional or planned ignoring is a widely used technique to manage handicapped children. Simply stated, the inappropriate behavior of children should be ignored. Since it is assumed that the child is desiring parent attention, to withhold it will decrease the undesirable behavior. Planned ignoring has been used effectively by parents when children are nagging them. It is also one of the most inadequately and overused techniques by parents. For this technique to be effective, withholding of attention is necessary. Often parents are effectively withholding their attention but other brothers or sisters are not ignoring the undesirable behavior. When this occurs, parents must not use the intentional ignoring strategy. For this technique to be maximally effective the parent must be able to ignore all brother, sister or peer behavior.

Sample Contract To Increase Studying

I, (child's name) agree to study the following subjects (Science & General Math) in my room beginning at (7:30 p.m.) to (9:00 p.m.) Monday through Thursday. I must turn in all homework assignments and obtain an average score of 70% on all of them for the first six weeks session. I must also obtain an average of 70% on all quizzes and projects in (Science and General Math for the first six weeks. If I meet criteria on the above subjects I will earn the following rewards:

1. (to invite a friend to spend Friday night)
2. (the right to study for my drivers test)
3. (to go out for the school basketball team)
4. _____

I can also earn a 50¢ raise on my allowance if I obtain 80% on all (Science & General Math) homework, projects or quizzes. If I do not meet (70%) criteria I will forfeit all privileges mentioned above.

_____
(Child's Signature)

_____
(Parent's Signature)

Response cost. Response cost is a technique whereby children are fined for exhibiting inappropriate behavior. Engaging in undesirable behavior costs the child. If a child gets into a fight they forfeit their allowance. If a child doesn't clean up their room they are fined 50¢. If a child doesn't take out the trash they aren't allowed to go outside after school to play. Fines have been used to decrease temper tantrums, swearing, stealing, and skipping school. Assess just enough of a fine to reduce the undesirable behavior.

Time out. Time out is a technique whereby children are placed into a setting away from all reinforcers for a specific period of time. It can be used for a number of inappropriate behavior such as hitting others, throwing objects, and property destruction. In such situations some children may need to be isolated to settle down and think about their behavior. Parents often tell their children to go to their rooms for 30 minutes for exhibiting a number of undesirable behaviors. But what they don't realize that a number of reinforcers may be in the child's room such as TVs, radios, headphones, computers, toys, etc. Thus, instead of serving as an isolation area to think about what they did, children can go to their rooms and play with a number of reinforcers.

To use time out effectively:

1. Select an area that is isolated, well-lighted and ventilated.

2. Select an area that is boring where no reinforcers are located.

3. When telling a child that he/she must move to time out act quickly, remain calm, tell the child why they are going to time out, tell them how long they must spend in time out, the rules to get out of isolation and escort them if necessary.

4. A kitchen timer can be used effectively to monitor the length of time.

5. If the child leaves the area before the time is up, return them to the area and tell them that the time must start over for leaving early.

Time out durations of not more than 30 minutes for younger children and 1 hour for teenagers is recommended. The shorter the time segment the better.

Punishment. Punishment is defined as the application of aversive stimuli. As a last resort intervention, punishment often results in the child receiving physical or corporal punishment. Major problems with its use include:

1. Punishment can result in physical injury to a child.

2. Punishment may result in guilt, frustration, excessive loss of control, etc. for parents.

3. Punished children may become punishing adults.

4. Punishment does not tell children what to do. It tells them what not to do.

Additional punishers often used by parents consist of criticism, verbal reprimands and screaming. Screaming at

children has been found to be least effective. If done to an excess, children tend to ignore or avoid such adults. Criticism and reprimands can be effective punishers if they are aimed at rejecting an undesirable behavior in order to increase a desirable behavior. Telling a child "No!" and then telling them what you want them to do is an effective mild use of punishment.

Conclusion

Although the birth of a handicapped child is an extremely stressful occurrence for that child's parents and family, the continuing source of stress resides in the daily incongruencies between the demands of the environment and the ability of the child to meet those demands. When the handicapped child fails to accomplish these demands, both the child and the parents experience frustration and stress. This frustration and stress may result in inappropriate behavior patterns on the part of the child and compound still further the stress experienced by the parents.

This paper has attempted to explain the sources of stress and some techniques which support personnel can use to help parents overcome this discrepancy cycle. Continual support services to meet the individual needs of families with handicapped children is advocated.

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